

Public Comment
Justin Reilly, esq.

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Chronic Fatigue Syndrome Advisory Committee
U.S. Department of Health and Human Services
CFSACDec2013@seamoncorporation.com

RE: Testimony for December 2013 CFSAC:
Recommendations (1) Endorsing Expert Letter re IoM,
(2) Demanding CDC Conduct Repeat CPET

Dear Ladies and Gentlemen of the Committee:

We have a short meeting today, so I will focus “like a laser” on our two most urgent issues. I respectfully request that you focus on and address these before moving on to anything else, as you may run out of time.

I plead with you to make two vital recommendations:

- (1) Endorsing the Letter of the now 50 ME Experts demanding HHS not contract with IoM to redefine ME and that HHS immediately adopt the ME/cfs Canadian Consensus Criteria; and
- (2) demanding that Repeat CPET be required in the CDC's multi-site study.

(1) Recommendation Endorsing the Letter of the now 50 ME Experts demanding HHS not contract with Institute of Medicine to redefine ME and that HHS immediately adopt the ME/cfs Canadian Consensus Criteria:

This is by far our most urgent issue and thus it is absolutely vital that you make the above recommendation, in my well-considered opinion.

At the last meeting, you reiterated your recommendation to HHS originally made at the October 2012 meeting: “that you will promptly convene (by 12/31/12 or as soon as possible thereafter) at least one stakeholders’ (ME/CFS experts, patients, advocates) workshop in consultation with CFSAC members to reach a consensus for a case definition useful for research, diagnosis and treatment of ME/CFS beginning with the 2003 Canadian Consensus Definition for discussion purposes.”

As has been noted many times, HHS blatantly disrespected you by claiming that the IoM process to redefine ME was a fulfillment of your recommendation. The IoM contract has none of the salient features of your recommendation. (a) It is not “a stakeholders’ (ME/CFS experts, patients, advocates) workshop in consultation with CFSAC...” (2) it will come up with a clinical definition not “a case definition useful for research, diagnosis and treatment” and (3) it will not “[begin] with the 2003 Canadian Consensus Definition for discussion purposes.”

The IoM contract is so dangerous that it has provoked a response from stakeholders that goes completely beyond those from the past. In the past, whenever HHS would make a move to retard or muddy the science, at most one or two experts would say anything, usually no expert would speak up at all. Now we have a letter demanding in the strongest terms, that there be no IoM contract and CCC be immediately adopted, and from no less than 50 of the nation’s and world’s top ME clinicians and researchers! This is backed up by the endorsement of the letter by over 170 patient advocates and over 3,000 petition signers. Never before has the ME professional and patient community come together with nearly unanimous voice to stop such a disaster.

The committee will cost \$1M, be composed primarily of non-experts (with a bias toward a psychosomatic view of ME, if the consistent statements about ME in the IoM GWI reports and the composition of the latest GWI IoM panel are any indication), and use an evidence-based medicine formula to screen papers (which will screen out many useful papers and vital expert experience and include many unscientific papers). All this when we have a stellar definition in the CCC which has been validated, operationalized, written by and adopted by the top ME clinical and research experts!

The IoM definition will be rolled out and disseminated vigorously with neither any of these steps nor any field testing having taken place!

Please stand firm with our experts, advocates, patients and supporters in insisting the contract be immediately terminated and CCC be immediately adopted.

(2) Recommendation that Repeat CPET be required in the CDC's multi-site study

Post-Exertional Relapse is the hallmark feature of ME, though Dr. Unger has stated otherwise. This is why she will not conduct Repeat Cardio-Pulmonary Exercise Testing in CDC’s multi-site study as it would reveal PER. Repeat CPET is a gold-standard technique in diagnosing and researching ME. It must be included in CDC’s multi-site study!

Thus, I strenuously suggest that today you make two absolutely crucial recommendations:

**(1) that Repeat CPET be required in the CDC's multi-site study and
(2) that you fully and strongly endorse the letter of the 50 ME experts demanding HHS not contract with IoM to redefine ME and that HHS immediately adopt the ME/cfs Canadian Consensus Criteria.**

Thank you for your consideration.

Sincerely,
Justin Reilly, esq.